

# *Caring for Your Loved One at Home*

A Guide for Caregivers



# *Your Hospice Team*



Nursing Team

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Counselor

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Hospice Aide

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Clergy

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Volunteers

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Care Team Support Center

Phone Number

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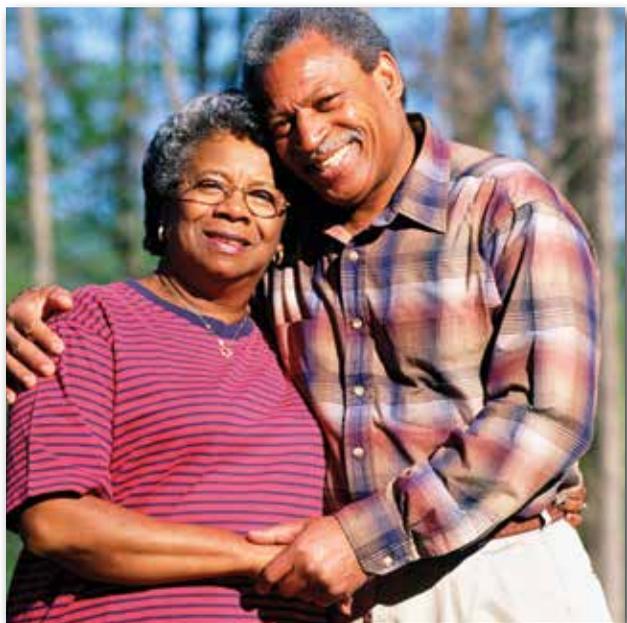
## *A Message to Caregivers*

Hospice care allows patients and families to make the most of the time they have together. While the days ahead may be physically and emotionally trying, as caregiver you have an opportunity to make a real difference in your loved one's life and also in your own. Caregiving is truly a gift of love.

Hospice is dedicated to providing supportive care to our patients and their families. This booklet contains practical information to help you, but it cannot answer all of your questions.

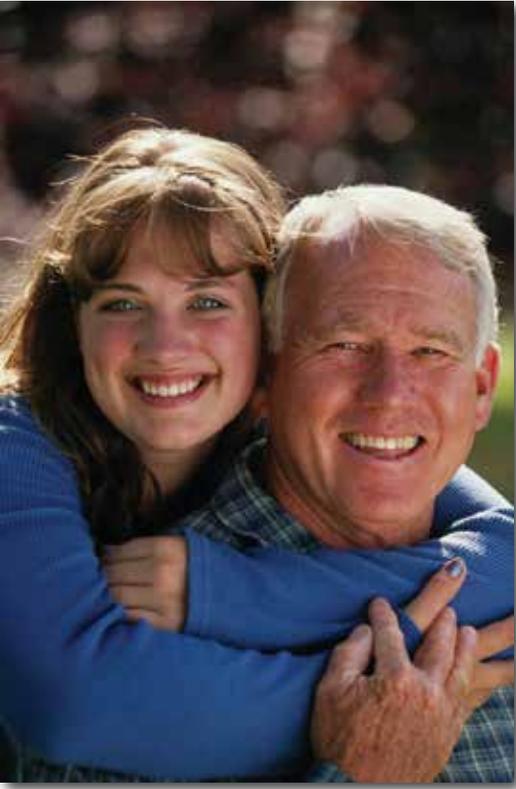
Do not hesitate to call Hospice when you need information that is not in this booklet, or just when you need to talk with someone who understands the highs and lows that caregivers experience each day.

We remind you that we are here for you twenty-four hours a day, seven days a week, whenever you need help.



*Caregiving is truly a  
gift of love.*

*Caring for your loved one at home*



*Hospice care is designed to support  
the whole family.*

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*Caring for your loved one at home*



*Allow friends and family  
members to help.*

## *Caring for the Caregiver*

The responsibility of caring for a family member at home can be overwhelming. As caregiver, you will have many physical and emotional demands placed on you.

It is important to take time for yourself and to ask for help. Protect your own health and well-being by:

- ◆ Eating balanced meals.
- ◆ Getting adequate rest.
- ◆ Planning regular times to get out of the house.
- ◆ Allowing friends and family members to help. They may not know how to offer, but it is important for you to ask for and accept help now.
- ◆ Minimizing your regular household tasks, or allowing others to do them for you.

Our Hospice volunteers are eager to lend a hand by running errands or visiting with your loved one while you take time for yourself. Again, don't hesitate to call us for help.

*What  
Your  
Loved One  
Might  
Say*



Your loved one may not be able to voice his emotional concerns now, but might make the following requests if he could.

- ◆ Don't avoid me. Continue to be my friend.
- ◆ Please overlook my appearance.
- ◆ Please include me in decision-making. I've been robbed of many things, but give me a chance to make decisions for my family and for myself.
- ◆ Help my family. Offer to do errands or offer to come stay with me to give them a break.
- ◆ Sometimes I need to talk about difficult subjects. Find out by asking me, "Do you feel like talking about it?"
- ◆ Don't feel like we always have to talk. Just sitting quietly is a wonderful gift.
- ◆ Hold my hand even if I don't seem to respond.
- ◆ Don't force me to eat or drink.

## *Patient Care*



*As a caregiver, you have  
an opportunity to make  
a real difference in your  
loved one's life and also in  
your own.*

## *Solving Common Problems*

We sometimes forget that many problems have easy solutions. Use this list to apply simple solutions to common problems. For more detailed information on some of the symptoms, refer to later sections of this booklet.

### **Pain**

- ◆ Give medication as ordered. Refer to the medication sheet in the Hospice folder.
- ◆ Help the patient change his physical position.
- ◆ Refer to the following chapter.

### **Nausea and Vomiting**

- ◆ Give medication as ordered. Refer to the medication sheet in the Hospice folder.
- ◆ Give clear liquids only.

### **Fever**

- ◆ Increase the patient's fluid intake as tolerated.
- ◆ Give your loved one a cool sponge bath. Use water, not alcohol.
- ◆ If the temperature is 100° F or higher, talk to your Hospice nurse about giving acetaminophen (Tylenol).

### **Constipation**

- ◆ Give laxative of choice.

### **Diarrhea**

- ◆ Give the patient clear liquids only.

### **Swelling**

- ◆ Elevate the swollen arm or leg on a pillow or folded blanket.
- ◆ Reduce the patient's salt intake.
- ◆ Talk to your Hospice nurse about giving a medication.

### **Leaky Foley Catheter**

- ◆ Place a Chux (blue absorbent pad) under the patient with the blue side facing away.
- ◆ Apply an incontinence pad.
- ◆ Check the catheter for bends or kinks.
- ◆ Call Hospice if the patient complains of stomach pain or the urge to urinate.

Call Hospice if these solutions don't help.

### **Call Hospice Immediately If Your Loved One:**

- ◆ **Has unusual bleeding**
- ◆ **Is increasingly short of breath**
- ◆ **Has a seizure**
- ◆ **Is in unusual or severe pain**
- ◆ **Suffers frequent nausea or vomiting**
- ◆ **Falls**



## *Pain Management*

Uncontrolled pain is often a patient's greatest fear when he becomes ill. In general, pain is helpful when it serves to let us know something is wrong. It tells us where the injury or illness is, and helps the doctor determine proper treatment.



When pain lasts beyond the time expected for tissue to heal, as it does with cancer or other terminal illnesses, it is considered chronic. Chronic pain is debilitating, it robs energy, it limits daily activities, and it interferes with the enjoyment of life.

When your loved one suffers chronic or severe pain, medication should be taken around the clock. The doctor may order time-release medication to keep him comfortable throughout the night. If, however, the medication requires a dose every 4 to 6 hours, we advise you to wake him to administer the medication around the clock.

Severe pain can be controlled by combinations of medications. Patients who take narcotics for pain do not become addicts. The right medications enable a quality of life not attainable by someone who is battling constant pain.

### **Finding the Problem**

Our staff must have accurate information about the nature of the pain in order to ensure that your loved one receives the correct medications for pain control. The nurse needs to know:

- ◆ Is the pain localized (in just one area of the body), or does the patient describe it as “all over?”
- ◆ Is the pain dull, throbbing, or sharp? What words does the patient use to describe it?
- ◆ Do certain activities or conditions (walking, eating, reading, for example) increase the pain?

## **Relieving the Pain**

Once pain medication is prescribed or changed by the doctor, the following steps will ensure the best pain relief:

- ◆ Administer pain medications exactly as ordered. Do not skip, double up, or stop a medication without consulting the Hospice team.
- ◆ Keep accurate records of the times and amounts of medication, and the effectiveness. This information can help the Hospice nurse determine if adjustments are necessary.
- ◆ Daily laxatives may be necessary; narcotics can cause constipation.
- ◆ Do not stop or decrease pain medication abruptly once the pain is under control.
- ◆ Remember, it is not how much pain we think the patient has, but how much pain the patient tells us he has.

## *Nausea*

Nausea may be especially troublesome for the first few days after pain medication is started. If it presents a problem, talk to your Hospice nurse. There is medication to help. Follow the instructions and schedule precisely.

These suggestions may also help to relieve or minimize nausea:

- ◆ Serve small meals, and encourage your loved one to eat slowly.
- ◆ Serve slightly salty foods and avoid sweets.
- ◆ Serve dry foods such as crackers and toast.
- ◆ Serve soft, bland foods such as rice, soft eggs, bland custards and apple juice.
- ◆ Avoid liquids at mealtime so your loved one doesn't feel over-full.
- ◆ Sucking on hard candy or ice chips may relieve nausea.
- ◆ Offer juice that has been frozen and chipped into small pieces.

## *A guide for caregivers*

- ◆ Encourage, but do not force liquids.  
Remember that the quality of the liquid is important when the patient does drink. Prune juice and other fruit juices provide calories and aid in bowel function. And, hot liquids stimulate bowel activity.
- ◆ Increase fluid intake by offering liquid-based foods such as Jello, sherbet, broths and soups.
- ◆ If your loved one is weak or has trouble holding a cup or glass, use drinking straws.



*Fruit juices provide  
nutrition and  
aid in bowel function.*

## *Bowel Hygiene*

The human body removes waste products through the elimination of urine and stool. Regular elimination is important to the patient's well-being. Problems concerning elimination can be a source of worry for the patient and can cause embarrassment, anxiety and discomfort.

To establish good bowel hygiene, follow these suggestions:

- ◆ Keep the bedpan or bedside commode near the patient to minimize the fear of "having an accident." Allow your loved one to have privacy during toilet use.
- ◆ Have soap, water and towel available for after toilet use. Clean the urinal, bedpan or commode immediately after use. Wash your hands thoroughly. Use room deodorizer, unless the patient is experiencing shortness of breath.
- ◆ Provide food that is adequate in dietary fiber if your loved one can tolerate it.

## **Constipation**

Dietary changes, medication, and stress interfere with normal elimination patterns. The disease itself might also interfere with elimination. Drinking hot liquids may stimulate bowel activity; however, the best treatment for constipation is prevention.

If your loved one doesn't have a bowel movement for a day or two, tell the Hospice nurse.

## **Diarrhea**

Diarrhea is characterized by frequent watery stools and stomach cramps. It can lead to loss of fluid and important minerals, causing dehydration. Keep a record of the number and frequency of watery stools. Notify the Hospice nurse.

## **Incontinence diapers**

A patient may lose the ability to control his bladder and/or bowels. If this happens, an adult incontinence pad or diaper is recommended. Your Hospice nurse will discuss your options with you.

Check diapers frequently and change them as necessary. Prolonged skin contact with urine and stool increases skin irritation and breakdown.

## *Help for Difficult Breathing*

When a person breathes in and out, oxygen (air) enters the lungs and carbon dioxide, a waste product, is removed. Many different health problems can make it difficult for the patient to get oxygen into his lungs. When this occurs, the patient will feel short of breath.

Other symptoms of low body oxygen are restlessness, anxiety, increased heart rate, or a bluish color to the nails and lips. When a person experiences shortness of breath, he may become anxious or frightened. It is very important to remain calm and reassuring. Assist your loved one to consciously slow down his breathing and increase the depth of his breaths. Specifically, do the following:

- ◆ Tell your loved one to be still and to relax.
- ◆ Help him sit up on the side of the bed or in a chair. If he is bedbound, raise the head of the bed upright or place pillows behind his head and back.
- ◆ Encourage him to breathe in through his nose and out through his mouth slowly, pursing his lips as if blowing out a candle.

- ◆ Keep smoke and strong odors away from your loved one. Do not use sprays such as deodorants, air fresheners, or bug sprays near him.

If your loved one's breathing does not improve, call Hospice. A nurse will come to your home to check his condition. Shortness of breath can be controlled by medication, oxygen or by eliminating stress or anxiety. In most cases, if a patient cannot absorb oxygen from the air, he may be unable to do so with supplied oxygen. Your Hospice nurse will assist you with the appropriate therapy.



*Encourage your  
loved one to relax.*



## *Nutrition*

Hospice patients may experience loss of, or decrease in appetite. As the disease progresses, your loved one will consume less and less food and drink. This can be upsetting to the family, but forcing food will only cause conflict. To avoid this struggle, try a few of these suggestions:

- ◆ Serve frequent small meals or snacks.
- ◆ Serve only favorite foods.
- ◆ Add a high protein supplement, such as a prepared instant breakfast drink.
- ◆ Let your loved one decide how much to eat.

If your loved one has lost his appetite...

- ◆ Don't force him or her to eat.
- ◆ Don't view the lack of appetite as your failure.
- ◆ Don't allow feeding to become the focus of your care.

## *Mouth Care*

Your loved one may experience mouth discomfort and gum sensitivity. Good mouth care increases overall comfort and improves appetite. Clean the patient's mouth gently but thoroughly twice each day.

### **Mouth Care Tips**

- ◆ Assemble a soft bristle toothbrush with a small amount of toothpaste, a small basin or bowl, a glass of lukewarm water, and a straw if the patient cannot sit up to drink.
- ◆ Help the patient to a sitting position if possible, or turn his head to the side towards you. Then brush the teeth as tolerated.
- ◆ If his mouth is tender, or tooth brushing is not possible, use sponge applicators (Toothettes). Gently swab the mouth and teeth with the moistened applicator.
- ◆ Chapstick or Vaseline keeps the lips moist, but don't use them if the patient is on oxygen. These products contain petroleum; a mixture of petroleum and oxygen can cause fire.
- ◆ Pierce the end of a Vitamin E capsule with a pin and smooth a few drops of the moisturizing oil on the patient's lips.

## *Bathing*

Daily bathing is important to all people, including those who are confined to bed. Good care of the skin promotes cleanliness, circulation and comfort. Ask your Hospice Aide to show you how to bathe your loved one if you're unsure.

If the patient has pain, schedule the bath 20 minutes after giving a regular dose of pain medication.

- ◆ Assemble your equipment before starting.
- ◆ Working from head to feet, soap an area of skin, rinse well, and pat dry.
- ◆ Make sure all skin folds and crevices are thoroughly dry to prevent chapping.
- ◆ Apply lotion to pressure areas and massage it in gently. Apply lotion to the patient's back and give him a back rub.
- ◆ If the patient can't tolerate a full bath because of pain or fatigue, try a partial bath. At least wash the face, hands, back and genitals daily.
- ◆ Shaving and hairstyling should also be a part of the bath time. Attention to personal grooming can really lift a person's spirits.

## *Skin Care*

It may be difficult to keep your loved one's skin in good condition. When a person is confined to bed, skin can break down over bony areas where pressure occurs. The resulting pressure sores or "bed-sores" are painful and difficult to treat. The following steps can help prevent your loved one from getting bedsores:

- ◆ Check the skin daily at bathtime for reddened areas. Report these to your nurse.
- ◆ Sprinkle cornstarch lightly over fresh sheets to reduce friction and help prevent irritation.
- ◆ Keep the bottom bedsheet tightly tucked in and free of wrinkles.
- ◆ If the patient spends significant time sitting in a chair or wheelchair, use gel-filled cushions to protect pressure points.
- ◆ Use lotion to massage all bony areas and around any noticeable reddened areas.
- ◆ Change your loved one's position frequently, using pillows for support.

## *Caring for your loved one at home*

- ◆ If movement causes pain, always wait at least 20 minutes after giving pain medication to change position.
- ◆ Avoid the use of rubber or plastic underpads on the bed. They trap moisture and prevent air circulation, which causes the skin to break down.

Even with the best of care, you may still notice reddened areas on your loved one's skin. Talk to your Hospice nurse for further suggestions.



*Use gel-filled cushions to protect pressure points.*



## *Home Safety*

### **FALLS AT HOME**

Each year, thousands of Americans fall at home. Many of them are seriously injured, and some are disabled. In recent years, more than 12,800 people over age 65 died and 1.6 million were treated in emergency departments because of falls.

Falls are often due to hazards that are easy to overlook but easy to fix. This section will help you find and fix those hazards in your home.

The checklist asks about hazards found in each room of your home. For each hazard, the checklist tells you how to fix the problem. At the end of the checklist, you'll find other tips for preventing falls.

## **HOME SAFETY**

### **FLOORS: Look at the floor in each room.**

- Move furniture in each room so you have a clear path to walk.
- Remove rugs not tacked down or use double-sided tape or a non-slip backing so the rugs won't slip.
- Pick up things like papers, books, shoes and other objects that are on the floor.
- Coil or tape lamp, telephone or extension cords and wires next to the wall so you don't trip over them.

**STAIRS AND STEPS: Look at the stairs you use both inside and outside your home.**

- Pick up papers, shoes, books and other objects on stairs so they are clear.
- Repair loose or uneven stairs or steps and make sure carpet is firmly attached.
- If you don't have a light over your stairway, use a flashlight at night.
- If light bulbs are burnt out, ask a friend or family member to change them.
- Fix loose handrails and try to have handrails on both sides of the stairs for better support.

**KITCHEN: Look at your kitchen and eating area.**

- Keep things you use often on the lower shelves.
- If you must use a step stool, get one with a bar to hold on to. Never use a chair as a step stool.

**BATHROOMS: Look at all your bathrooms.**

- Put a non-slip rubber mat or self-stick strips on the floor of the tub or shower.
- Consider grab bars inside the tub and next to the toilet to assist with balance.

**BEDROOMS: Look at all your bedrooms.**

- Place a lamp close to the bed where it's easy to reach.
- Plug in a night-light so you can see where you are walking at night. Some night-lights go on by themselves after dark.

**Other Things You Can Do to Prevent Falls**

- Have your doctor or pharmacist look at all the medicines you take, even over-the-counter medicines. Some medicines can make you sleepy or dizzy.
- Get up slowly after you sit or lie down.
- Wear shoes both inside and outside the house. Avoid going barefoot or wearing slippers.
- Improve the lighting in your home. Consider brighter light bulbs. Florescent bulbs are bright and cost less to use.

**Other Safety Tips**

- Keep emergency numbers in large print near each phone.
- Put a phone near the floor in case you fall and can't get up.
- Think about wearing an alarm device that will bring help in case you fall and can't get up.



*“Last Saturday,  
our son helped us  
move our furniture.  
Now all the rooms  
have clear paths.”*



## **Fire Safety**

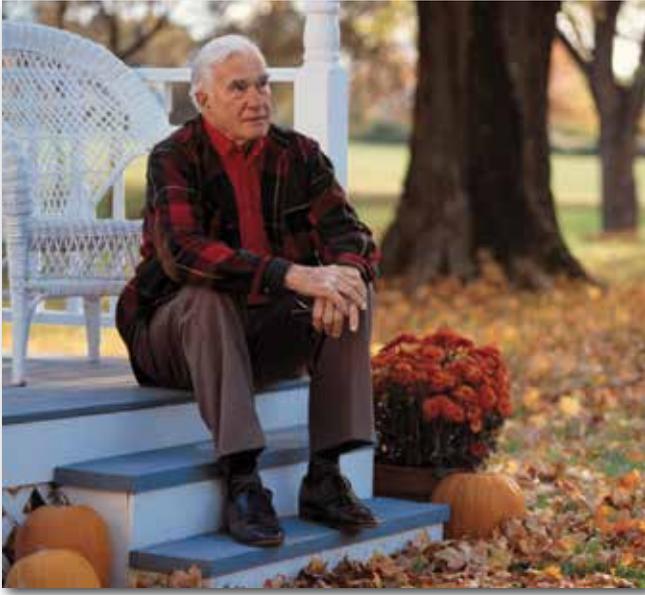
**To protect yourself and those you care about, follow these seven tips:**

- **Install and Maintain Smoke Detectors:** Consider installing smoke detectors on every level of your home, especially near sleeping areas.
- **Use Smoking Materials Safely:** Never smoke in bed, while drowsy, or while under the influence of medication or alcohol.
- **Pay Attention to Your Cooking:** Keep pot handles turned inward, and keep cooking surfaces and surrounding areas free from clutter and grease build-up. Use pot holders and oven mitts. Avoid wearing loose clothing with flowing sleeves while cooking. Take a reminder with you if you must leave the kitchen with food cooking on the range top.
- **Heat Your Home Safely:** Consider having a professional service all heating equipment annually. Keep anything that can burn or melt away from all heaters, furnaces, fireplaces, and water heaters. Never use a range or oven to heat your home.

- **Practice Electrical Safety:** Never overload the electrical system. Plug each appliance directly into its own outlet and avoid using extension cords.
- **Keep Matches and Lighters Away from Children:** Store matches and lighters in a locked drawer or a high cabinet away from the reach of children. Make sure lighters are child-resistant.
- **Know What to Do in Case of Fire:** Practice two ways out of every room in your home. Get out as soon as you discover a fire; do not try to fight the fire or gather possessions. Once out of the house, immediately dial 9-1-1 preferably from a neighbor's phone.



## *About the Final Days and Grief*



*Each person works through  
grief his or her own way;  
there is no one right way to  
experience it.*

## *Signs of Approaching Death*



As your loved one approaches death, the physical body enters the final stages of slowing down. The patient begins to withdraw emotionally. The most appropriate kinds of care at this time are comfort-enhancing measures. Many of the tasks described in

this manual are no longer necessary. Your emphasis should be on support and comfort for your loved one.

The following signs of impending death can help you understand what *may* happen. Often a patient will show some of these signs and then, for unexplained reasons, his condition may improve for a while before it deteriorates again. This could happen several times during the last months. Changes like this, back and forth, could be physically and emotionally draining on you and your family. Remember, you are not alone. As death approaches, the Hospice team will usually visit more often to offer support.

Caregivers who are not prepared for death may be inclined to call 911. This may be very traumatic for a dying patient and bring an unpleasant ending to life. It is appropriate to call Hospice at any time during the day or night.

### **As Death Nears**

You may notice some of the following changes when death is near:

- ◆ Your loved one's skin may become increasingly cool, especially on his arms and legs. The skin may appear bluish due to slowing circulation. Keep him warm with blankets.
- ◆ He may have a temperature up to 105°F. The body's thermostat is failing due to the decreased circulation. Gentle, cool sponging could be comforting.
- ◆ He may sleep more, and be difficult to rouse. Spend time with him when he's alert. Remind family members not to talk in front of your loved one as if he were not there. Never assume the patient cannot hear. Hearing is often the last sense to be lost, even in deep sleep.
- ◆ Your loved one may become confused about the time, place and persons surrounding him. Continue to identify yourself and speak directly to him.

## *Caring for your loved one at home*

- ◆ Bowel and bladder function may be lost. Adult diapers may be helpful.
- ◆ Noisy breathing occurs when mucous collects in the throat. Remember, suctioning and oxygen do not help at this stage. Gently turn the patient's head and let gravity help drain the secretions.
- ◆ Restlessness and repetitive motions such as pulling at bed linen may occur. Do not attempt to restrain your loved one. Continue to speak and act calmly. Assure him that it is all right to relax.
- ◆ Urination may decrease.
- ◆ Appetite for food and drink may cease. Do not force eating and drinking, but do provide mouth care with lemon-glycerin swabs.
- ◆ You may note changes in breathing cycles. Irregular breathing patterns are common. Comfort your loved one by elevating his head.
- ◆ He may make involuntary movements and sounds, such as grimacing and moaning. These actions do not necessarily indicate increased pain. Your Hospice nurse will help you assess pain and offer advice. Continue to give the pain medication as ordered.
- ◆ He may have hallucinations because he is detaching from this life. Affirm his experience; it is perfectly normal.

Give your loved one permission to let go. A dying patient will normally try to hold on if he doesn't sense your approval. Your assurance that it is all right to let go will assist in his peaceful death.

## *When Death Occurs*

Although you have prepared for the death of your loved one, the actual moment of death still may be a shock. Therefore, before death occurs, you and your family should discuss what to do when it happens.

If a member of the Hospice staff is not with you at the time of death, call the office and inform us immediately. A nurse can be sent to help you. You may also call friends or family members who will want to come to the home at this time.

Take as much time as you need to be alone with your loved one. Allow each family member time to say good-bye. This is very important in the grieving process. Crying is a healthy expression of grief.

You are welcome to help the nurse prepare your loved one for the funeral home. As part of this preparation, the nurse is required by the Medical Examiner to destroy all of the unused prescription medications.



## *Bereavement Services*

Each person works through grief in his own way; there is no one right way. The time following death is very important and should not be rushed. If you experience a sense of relief, you should not feel guilty. You are experiencing normal emotions.

Later the sadness and grief will come. The Hospice bereavement staff can keep in touch through visits and phone calls to help you through this period, if you wish. They can also give you information on bereavement support groups in your area. If you choose not to use these services right away, you are still eligible for them later if you desire. Bereavement groups are also available without cost to any family member or friend who is grieving.

Later you may also wish to attend special workshops and seasonal Time for Remembrance services. The Hospice bereavement staff will notify you about these events.

### **Tips to Help You Cope with Your Loss**

- ◆ Healing has progressions and regressions—it is full of ups and downs, dramatic leaps and depressing backslides. But positive experiences will return.
- ◆ Seek comfort. Accept support from others, and seek it out if you need to. It is human and courageous to do so.
- ◆ Be gentle with yourself. You have suffered a disabling emotional wound, so treat yourself with care.
- ◆ It's okay, in fact normal, to feel depressed. Crying is a cleansing release.
- ◆ Keep a journal. Putting your thoughts on paper is a good way to get them out. Later you can look back and see how far you've come.
- ◆ Heal at your own pace. Never compare the duration of your grief with someone else's.
- ◆ Give yourself praise. In caregiving, you have committed an incredible act of love. Now you must learn to care for yourself with the same tenderness.



## *The Children's Assistance Program (CAP)*

Children may express grief in ways similar to that of adults but they are just as likely to express grief in ways not recognizable to adults. Included in HPH Hospice's circle of care are pediatric counselors who assist children and their families in coping with the grief they are likely to experience when a loved one is dying. After the death, our counselors can visit children and their families at home, in their school, or community, offering additional counseling.



*Children need continuous support from the adults they depend on.*

- ◆ Speak with the child at his own level. Young children need concrete information while older children can handle abstract concepts. Don't overwhelm children with more information than they can handle.
- ◆ Be alert to behavior problems at home or at school. Most minor problems take care of themselves, with your love and understanding. But don't hesitate to seek advice from our CAP counselor.
- ◆ Don't shield your child from information about death. During this time, children need continuous support from the adults they depend on.
- ◆ Call CAP if you have any questions or concerns about your child's bereavement.

*Caring for your loved one at home*

## *Helpful Information*



*Remember to call your  
hospice counselor if you  
have any questions.*



## *Survivor's Checklist*

You will need to inform others of your loved one's death and settle your loved one's estate. The checklist on the following pages can help you through this process.

Most funeral homes will assist you in obtaining copies of the death certificate and applying for certain death benefits. If you need further assistance, please call your hospice counselor.

- ◆ Make a list of family and friends who will need to be notified of the death.
- ◆ Obtain additional death certificates from the health department. You will need several copies to process death benefits.
- ◆ Notify Social Security at 1-800-772-1213.
- ◆ Notify and process claims for life insurance. Process any veteran's claims through 1-800-827-1000.
- ◆ Record the death certificate at the county courthouse for possible tax reductions.
- ◆ Change automobile title and insurance policies to the survivor's name.

## *Caring for your loved one at home*

- ◆ Notify your bank of the death. It may be helpful to keep both names on the checking and savings accounts for up to one year after the death.
- ◆ Change deeds, utilities, stocks, bonds and other investments to the survivor's name.
- ◆ Make necessary changes in your will. Update any advance directives that may include your deceased loved one's name.
- ◆ Change or cancel all credit cards immediately.
- ◆ If your loved one lived alone, notify the post office and have mail forwarded to you or to the executor of the will.
- ◆ If your loved one rented, notify the landlord and set up a time to remove all belongings.
- ◆ Check with credit unions, trade unions, credit card companies, auto clubs or other member organizations for possible pensions or additional benefits.
- ◆ Notify the driver's license bureau.
- ◆ Make a list of people you wish to thank for gifts or other acts of kindness.
- ◆ Consult an attorney if you are uncertain or unable to settle your loved one's estate.



## *In Case of Severe Weather*



During the year, you may be required to evacuate your home due to severe weather. Your loved one will be most comfortable if you can evacuate to the home of family or friends, or even to a hotel. Use public evacuation shelters as a last resort. Wherever you go, bring along all medication, transportable medical equipment and the Hospice folder. Your Hospice nurse will help coordinate transportation of larger medical equipment if needed.

Before it becomes necessary, familiarize yourself with proper evacuation routes, emergency shelter locations *that provide health care staff*, and general emergency preparedness information. If your family needs evacuation assistance from the county, you must pre-register: All of this information is available through the numbers below.

### **In Pasco County: Disaster Preparedness**

Dade City	(352) 521-4274
Land O' Lakes	(813) 996-7341 ext. 8137
New Port Richey	(727) 847-8137

### **In Hernando County**

Emergency Management	(352) 754-4083
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### **In Citrus County**

Emergency Operations Center	(352) 746-6555
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The Hospice team will help you develop an evacuation plan.

If you must evacuate to a public emergency shelter, understand that a caregiver must stay with the patient at all times; the county does not provide staff to care for unattended patients. If the patient lives alone, a care plan will be prepared to meet individual circumstances.

## **What to Take to an Emergency Shelter**

If you must evacuate to a shelter, take the following, labeled with the owner's name:

- ◆ Medication in correctly labeled vials
- ◆ Hospice folder
- ◆ Special equipment and supplies, such as oxygen equipment, dressings, diapers
- ◆ Lawn chair, blanket, and cot or sleeping bag
- ◆ Personal hygiene items
- ◆ Change of clothing
- ◆ Flashlight with extra batteries
- ◆ Portable radio
- ◆ Nonperishable special diet foods
- ◆ Identification

## **Do Not Take**

- ◆ Alcoholic beverages
- ◆ Pets
- ◆ Weapons
- ◆ Valuables
- ◆ Perishable foods

## *Financial Concerns*

We understand the difficulty you faced when you decided to accept Hospice. Contributing to those concerns may be questions about cost. This section explains how hospice care is covered by most reimbursement sources.



HPH Hospice is a non-profit organization. We provide care regardless of your ability to pay and accept assignment from Medicare, Medicaid and insurance that covers hospice care.

## **Medicare**

The Hospice Medicare Benefit was established in the early 1980s. Included under Medicare Part A, the hospice benefit covers the following if they are within your plan of care as determined by you, your physician and Hospice:

- ◆ Care by the hospice interdisciplinary team.
- ◆ Medications for this illness.
- ◆ Necessary medical equipment.
- ◆ Doctor's visits for this illness.
- ◆ Hospitalization for this illness.
- ◆ Lab, x-ray and other ancillary services related to this illness.

To be eligible for the Hospice Medicare Benefit, the patient must qualify for Medicare Part A and be certified by a physician to be terminally ill and having a prognosis of six months or less if the disease follows its normal course. Medicare pays Hospice directly for routine care related to the terminal illness. Aggressive, curative or experimental treatments are beyond the scope of the hospice benefit. Treatment for other medical services unrelated to the terminal illness is covered under Medicare Part B. Your primary physician will continue to bill Medicare directly for these services.

HPH Hospice pays for care related to the terminal illness that is within the approved plan of care. Any changes to your plan of care must be approved by Hospice if we are expected to pay. Please be sure your doctor consults with Hospice before beginning any new course of treatment.

You have the right to end hospice coverage at any time. If you decide to do so, Medicare Part A coverage will resume immediately.

### **Medicaid**

If you are not eligible for Medicare, you may qualify for a state program called Hospice Medicaid. A hospice counselor can determine your eligibility and assist you with the application process. If you do qualify, your benefits will be similar to the Medicare benefits discussed above.

### **Insurance**

Coverage under different insurance carriers varies. If you have a private insurance plan, Hospice will help you determine eligibility. Most insurance plans cover hospice services fully or in part.

If you have any concerns about your financial responsibilities, please call your HPH Hospice counselor for assistance.



## *Know Your Rights and Responsibilities*

Respecting the individuality of every patient and family is the cornerstone of hospice care. HPH Hospice encourages you to familiarize yourself with your legal rights and responsibilities as a hospice patient.

### **You Have the Right...**

*To be cared for* by a team of professionals that will provide quality, comprehensive hospice services as needed and appropriate for you and your family (including extended and alternative family).

*To have a clear understanding* of the availability of and access to hospice services and the teams that visit regularly and are on call 24 hours a day, seven days a week.

*To appropriate and compassionate care*, regardless of diagnosis, race, age, gender, creed, disability, sexual orientation, place of residence or ability to pay for services rendered.

*To be informed* regarding your health status in order to participate in the planning of your care.

*To be informed* regarding potential benefits and risks of all medical treatments or services suggested, and to accept or refuse all treatments and/or services as appropriate to your personal wishes.

*To be treated* with respect and dignity for your person, family, caregivers and property.

*To have your family and/or caregivers trained* in effective ways of caring for you when self-care is no longer possible.

*To expect confidentiality* with regard to information concerning your health status, as well as social, and/or financial circumstances.

*To voice grievances* concerning patient care, treatments and/or respect for person or privacy without being subject to discrimination or reprisal, and have any such complaints investigated by Hospice.

To report suspected Medicare Fraud please call toll free 866-417-2078.

To report suspected Medicaid Fraud please call toll free 866-966-7226.

**You Have the Responsibility...**

*To participate* in developing your plan of care and updating it as your condition or needs change.

*To provide* Hospice with accurate and complete health information.

*To remain under a doctor's care* while receiving hospice services.

*To assist hospice staff* in developing and maintaining a safe environment for the provision of your care.



## *How You Can Help*

Many families ask how they can help, and to show their appreciation for the incredible love and care they've been shown. The greatest gifts back to HPH Hospice are gifts of time, talent or expertise, and donations of money and your gently used treasures.

Gifts may be made by cash, check, credit card, stocks, in your Will or a donation to one of our thrift stores. Make a secure on-line gift at [www.hph-hospice.org](http://www.hph-hospice.org) or call (800) 486-8784.

Mail a check to:

HPH Hospice

ATTN: Donations

12107 Majestic Blvd.

Hudson, FL 34667

Whichever method of giving you choose, please know that your contributions to HPH Hospice are used to provide the utmost care for our patients and families. It will give you the satisfaction of knowing that you have made a difference in the lives of those around you. All Donor Information is kept strictly confidential unless we receive written consent to release information from the donor.

If you have questions, call, 727-819-5909 or (800) 486-8784.



# *Important Phone Numbers*

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Patient's Name

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Caregiver's Name

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Physician's Name

Phone

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## **Funeral arrangements to be handled by**

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Funeral Home

Phone

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## **Family and Friends**

---

Name

Relationship

---

Home

Cell

Work

---

Name

Relationship

---

Home

Cell

Work

---

Name

Relationship

---

Home

Cell

Work



## **HPH Hospice**

### **Administrative Office**

12107 Majestic Blvd.  
Hudson, FL 34667  
(727) 863-7971 | (800) 486-8784

### **South Pasco**

6807 Rowan Rd.  
New Port Richey, FL 34653  
(727) 848-7160

### **West Hernando**

12260 Cortez Blvd.  
Brooksville, FL 34613  
(352) 597-1882

### **North Pasco**

12029 Majestic Blvd. Suite 1  
Hudson, FL 34667  
(727) 863-9522

### **East Hernando**

698 South Broad St.  
Brooksville, FL 34601  
(352) 796-2611

### **East Pasco**

37445 Clinton Ave.  
Dade City, FL 33525  
(813) 780-6797

### **Citrus**

3545 N. Lecanto Hwy.  
Beverly Hills, FL 34465  
(352) 527-4600

## **HPH Thrift Stores & More**

6528 Massachusetts Ave.  
New Port Richey, FL 34653  
(727) 841-7356

4910 Allen Road  
Zephyrhills, FL 33541  
(813) 355-4830

[www.HPH-Hospice.org](http://www.HPH-Hospice.org)